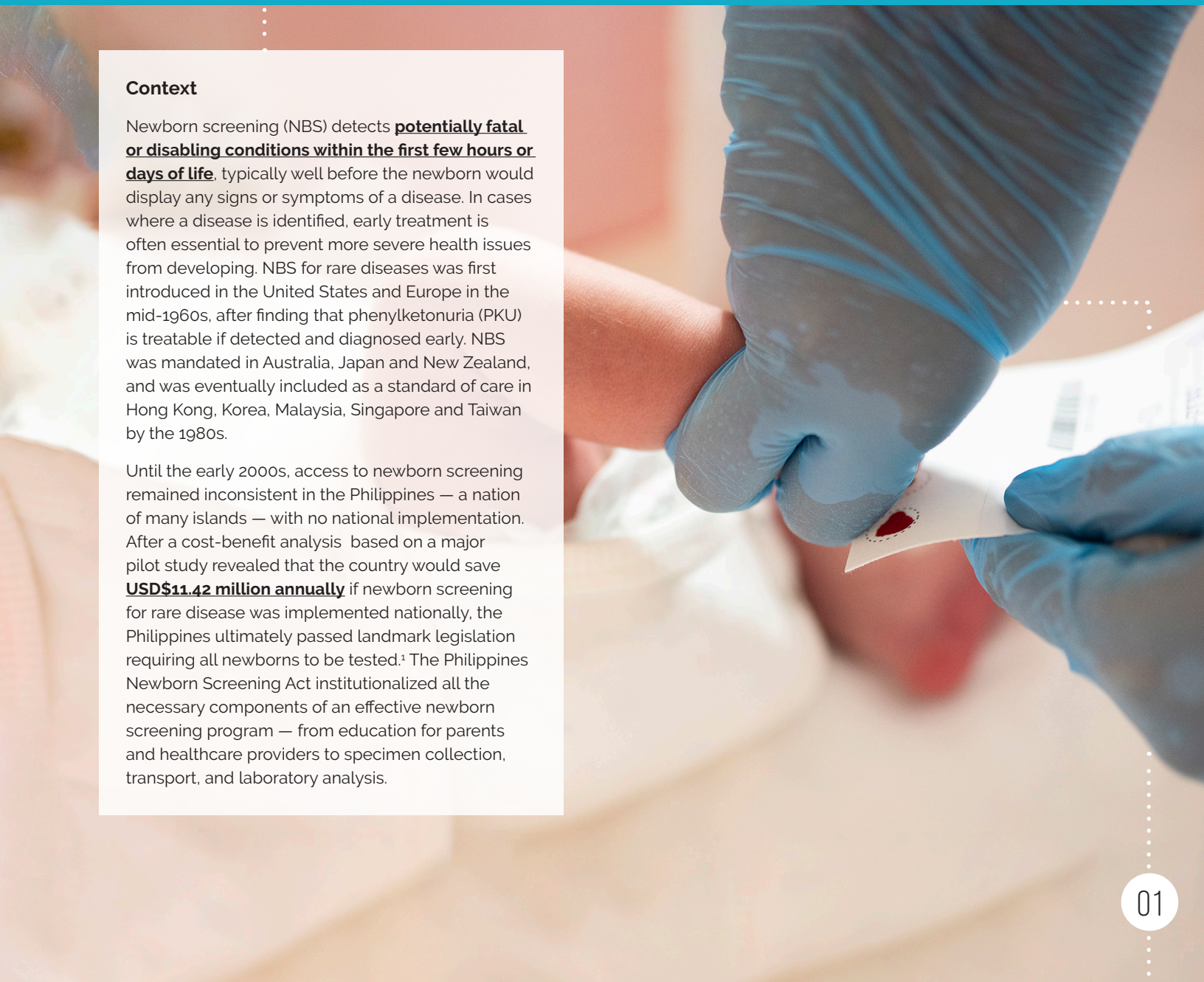
CASE STUDY: Philippines Newborn Screening Act (Philippines)

PILLAR: Policy

Driving policy to adopt newborn screening in the Philippines



Context

Newborn screening (NBS) detects **potentially fatal or disabling conditions within the first few hours or days of life**, typically well before the newborn would display any signs or symptoms of a disease. In cases where a disease is identified, early treatment is often essential to prevent more severe health issues from developing. NBS for rare diseases was first introduced in the United States and Europe in the mid-1960s, after finding that phenylketonuria (PKU) is treatable if detected and diagnosed early. NBS was mandated in Australia, Japan and New Zealand, and was eventually included as a standard of care in Hong Kong, Korea, Malaysia, Singapore and Taiwan by the 1980s.

Until the early 2000s, access to newborn screening remained inconsistent in the Philippines — a nation of many islands — with no national implementation. After a cost-benefit analysis based on a major pilot study revealed that the country would save **USD$11.42 million annually** if newborn screening for rare disease was implemented nationally, the Philippines ultimately passed landmark legislation requiring all newborns to be tested.[1] The Philippines Newborn Screening Act institutionalized all the necessary components of an effective newborn screening program — from education for parents and healthcare providers to specimen collection, transport, and laboratory analysis.

Philippines Newborn Screening Act

Overview of program

The Philippines Newborn Screening Project (PNSP) started as a pilot in 1996 to determine the occurrence of five prevalent conditions in the country: congenital hypothyroidism, congenital adrenal hyperplasia, phenylketonuria, galactosemia, and homocystinuria. The goal of PNSP was to generate data that would show the national government the value of newborn screening.

PNSP was a collaboration among pediatricians and obstetricians from the 24 hospitals in the greater Manila area (18 private, 6 government), and was funded by a small fee (USD$10) charged to parents for screening. The project used different multimedia communication methods to convey the benefit of a newborn screening test. For example, each participating hospital displayed posters that promoted preventive screening, national television and radio campaigns featured people living with a rare disease who spoke about the value of NBS, and other approaches highlighted the relatively low cost of screening compared to everyday purchases, such as a bottle of soda or cigarettes. These varied marketing tactics proved effective in encouraging new parents to participate and pay the small fee for the test.

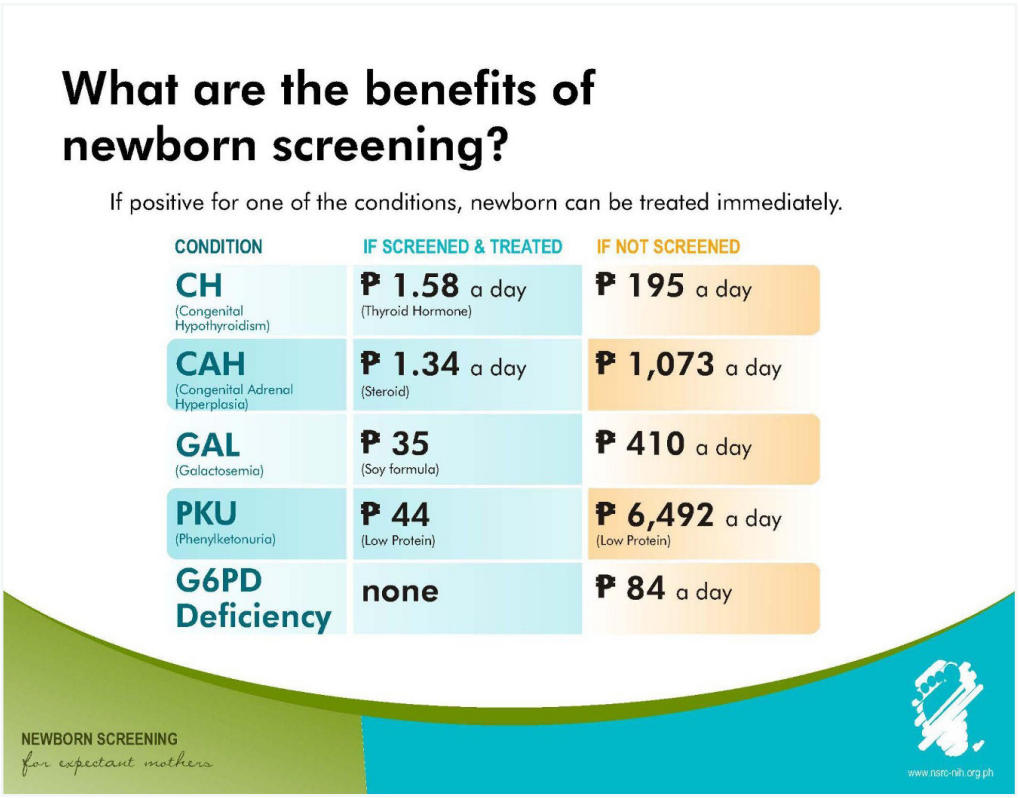


Figure 1: Value of NBS poster

To help ensure the success of the pilot, every hospital had four newborn screening coordinators, two from pediatrics and two from obstetrics, who initially met monthly to discuss progress in implementation. Later, nurses, medical technologists, midwives and general practitioners also became involved in this effort once they learned about the value of newborn screening.

Working across borders

Since the Philippines did not have a newborn screening laboratory during the first year of the project, hospitals sent samples daily to the New South Wales Newborn Screening Laboratory in Australia — which was costly and time consuming. In 1997, the country established its first newborn screening laboratory at the National Institutes of Health.

At the same time, rare disease advocates in the country began collaborating with other newborn screening programs in Australia and the U.S. on technical and policy issues. Technical staff went to both countries for laboratory training and experts from these two countries worked with the Philippines team to ensure that the country's new lab met accreditation standards. In 2000, PNSP received a five-year grant from the International Atomic Energy Agency to aid newborn screening programs with an emphasis on radiochemical methods for congenital hypothyroidism screening. As part of the grant, the team had further access to international experts who helped strengthen the program, especially implementation of lab systems.

The U.S. Centers for Disease Control and Prevention and Taiwan's Preventive Medicine Foundation continue to provide expert consultation on maintaining strong testing labs and newborn screening labs is now formally accredited by the Philippines' Department of Health every three years.

On the policy side, advocates from the Philippines interviewed NBS leaders in the U.S. to understand the challenges with drafting and adopting NBS legislation to help inform their strategy to get a NBS policy enacted.

The power of data

After five years of advocating to the Department of Health, NBS legislation began to advance. The data generated in the first two years of the PNSP were critical to mobilizing support for the Newborn Screening Act. For the first time, there were solid numbers on the prevalence of the five rare conditions included in the testing panel. Advocates used these figures to develop a cost-benefit analysis which showed that screening for all five disorders simultaneously resulted in a net benefit of US$11.42 million, clearly demonstrating the economic value of newborn screening.

Elements of the cost-benefit study were converted into an easy-to-understand visual presentation to explain the cost savings of newborn screening to parents and aid their decision about whether to get their newborn tested. For example, a table showed that if a baby with congenital hypothyroidism is saved because of early detection, the cost of treatment is less than P2 ($0.03USD) per day, but if the baby's condition is not detected and does not survive, the cost is about P200 ($3.46USD) a day.

Mobilizing diverse advocates

During the advocacy efforts (2003-2004), 20 organizations, including government agencies, medical societies, and religious organizations, sent letters of support for the NBS bill. Physicians, nurses, and midwives attended public hearings at the Senate and House of Representatives. Although legislation in the Philippines usually takes a decade to pass, the newborn screening bill was adopted in less than a year — which was unprecedented. The quality of data generated by PNSP, as well as the support from the rare disease community, including support from nuns, religious communities, and health professionals were key success factors.

The 2004 NBS Act declares that "the State shall institutionalize a national newborn screening system that is comprehensive, integrative and sustainable, and will facilitate collaboration among government and non-government agencies at the national and local levels, the private sector, families and communities, professional health organizations, academic institutions, and non-governmental organizations."

The Act establishes a framework for national implementation — including integration into the public health system — and provides screening access for all newborns, placing responsibility on health practitioners to inform parents of the benefits of screening. Importantly, the Act requires that NBS is included in the benefit package of social insurance — solving the funding challenge for families and ensuring equitable access to lifesaving diagnosis. Lastly, the Act created accountability mechanisms for health facilities to comply by including NBS in the requirements for hospitals and birthing facilities to maintain both their license to operate and their accreditation to participate in national health insurance.

In addition to the NBS Act, the Philippines established the Performance Evaluation and Assessment Scheme tool in early 2000s to monitor the quality improvement of newborn screening program implementation at various newborn screening centers.

Results

As a result of the NBS Act and the power of early detection, close to 300,000 babies have been spared the potential harm of a rare disease. The number of facilities offering newborn screening in the Philippines increased from 24 in 1996 to 7,134 in 2023. The hospitals and birthing centers that offer NBS are spread out across the Philippines' 7,600+ islands. Since the NBS Act, the number of disorders being screened increased from 5 to 30, a combination of common and rare disorders.

The program demonstrated resiliency during the COVID pandemic. Despite operational problems (such as shutdowns of courier services and closed provincial borders), samples reached labs thanks to the assistance of agencies that could cross borders, such as police, fire, military, and navy.

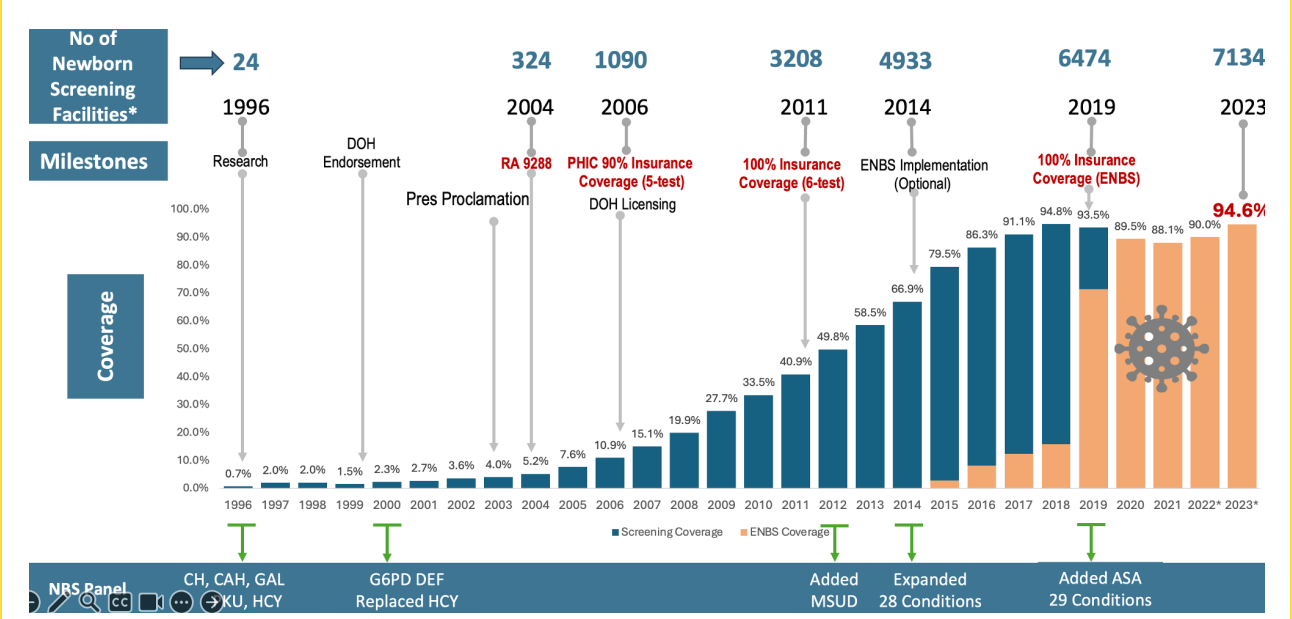


Figure 2: Evolution and reach of NBS programs in the Philippines; NBS panel includes congenital hypothyroidism, congenital adrenal hyperplasia, henylketonuria, galactosemia, and homocystinuria, glucose-6-phosphate dehydrogenase deficiency, and maple syrup urine disease.

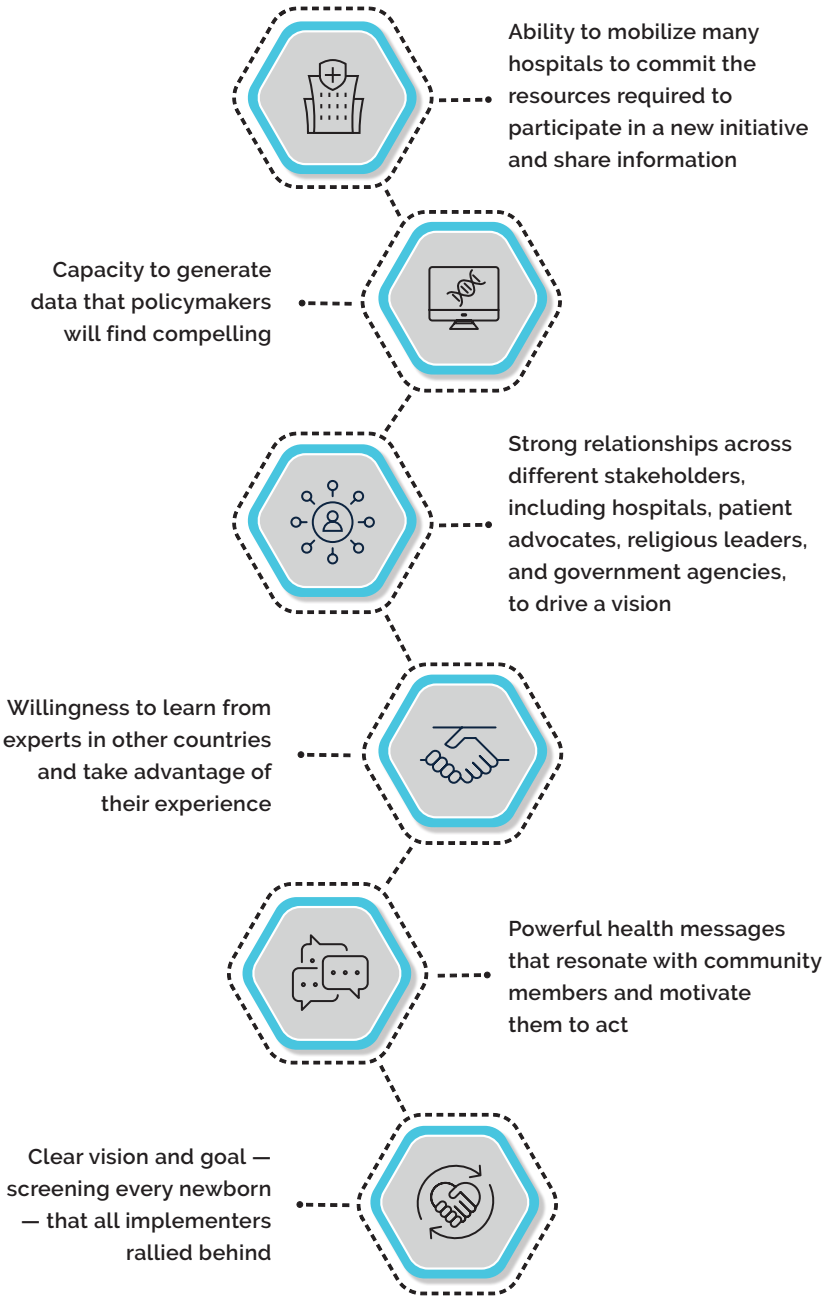
Learnings

- **Data drives decision making:** In one of the early meetings at the DOH, health officials said, 'No data, no policy'. The team behind the Philippines' Newborn Screening Project realized that generating compelling data would be critical to advance newborn screening legislation and get it passed quickly.
- **Early government buy-in is essential:** Getting government support from the outset in the planning and implementation process was crucial, especially buy-in from local governments to encourage parents to pay for screening their newborns. The close collaboration with the Philippines government was also important because it subsidized the cost of testing for families that could not afford to pay.
- **Funding does not have to be a barrier to test solutions:** The PNSP program was possible because the team was resourceful in securing funding from multiple sources, including direct fee-for-service, insurance coverage, and international grants. Eventually, the government covered the fee for newborn screening as part of the NBS Act, enabling the program to be sustained for long-term impact.
- **Community engagement and buy-in cannot be underestimated:** To implement a program of such scale, commitment from the community was essential. Families had to understand the value of the test and agree to participate, otherwise the project could not generate the data needed to drive policy change. Community involvement from local leaders in advocacy efforts also facilitated the rapid passage of the NBS law.
- **NBS programs should fit within the health care infrastructure.** From the beginning of PNSP, the goal was to integrate newborn screening into the national health system. Collaboration with testing labs in Australia enabled the Philippines team to figure out how to create its own infrastructure for newborn screening, enabling an easier transition once the Newborn Screening Act went into effect.
- **Other countries are willing to help:** The Philippines team benefitted in several ways by building strong relationships with Australia and the U.S., in particular. These countries provided lab testing during the first year of the pilot project, training in lab systems, and guidance on policy development — invaluable support in developing and implementing a full-fledged newborn screening program.

Goals & next steps

Today, nearly 30 years after the PNSP and 20 years after the passage of the Newborn Screening Act, the implementers continue to strengthen the program. Upcoming priorities include improving the quality of collected samples, monitoring long-term outcomes of children diagnosed with a rare disorder, screening 100% of babies born in the country, and generating more research on patient outcomes.

Success factors & considerations



References

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